Olmstead Work Group Meeting

San Diego, November 22, 2002

ASSESSMENT

Stakeholder Responses to Key Questions

The following comments were offered by stakeholders at the November 22, 2002 meeting of the Olmstead Work Group in San Diego. The comments are listed under each of the Key Questions that were discussed. Some sub-groups offered supplemental comments, which are included at the end. The comments of the participants in all four sub-groups have been combined; where stakeholders in more than one Work Group offered similar comments, only one is reported here in order to avoid unnecessary duplication.

1. What is the purpose of assessments?

- *Determine all factors, services and housing, physical and emotionally supports, that might be necessary for success in community placement
- *Determine all factors, services and housing, physical and emotionally supports, that might be necessary to deflect placement in institutional setting
- *Assess true desire of individual being assessed
- Use assessment to develop plan
- Assess for what a person can do, not what they can't do
- Use data on unmet needs for system
- Provide guidance to transition workers
- Give consumers and family the tools they need to make choices.
- Enable families to access services provided by school systems
- Identify community resources that address individual functional barriers for individuals who do not oppose community placement.
- Duality in planning – assess in environment & needs in the community
- Individualized process looking at most integrated setting
- "Holographic screen" – know all options available – have template to provide guidance.
- Cultural considerations
- Family situation & involvement

* = priority recommendations

2. Who should be assessed?

- Everyone in a restrictive setting should be assessed [do not assume that severe disability should automatically negate need for continuous or routine assessment]
- Anyone in licensed state facility
- Anyone referred by family or friend or ombudsman
- Anyone who asks
- People at risk of placement in a more restrictive setting
- Individuals going into & leaving high school
- Expand beyond “Medicare-Medi-Cal” identify need & expand
- People experiencing an unplanned medical crisis
- Anyone covered by the ADA
- Persons served by senior services systems
- People not opposed to community placement
- People at risk of placement in a: Children’s shelter,Nursing facility, Sub-acute facility,Institution for Mental Disease (IMD),Developmental Center, State Hospital,Large Community Care Facility,Inpatient Facility, Intermediate Care Facility, Juvenile Facility,Trauma Center
- (Did not reach a consensus re incarcerated imprisoned population)
- (Further study is needed to determine what factors to use when identifying “at risk”)

3. What information do consumers need so they can participate fully in their own assessment?

- Information should be provided via a facilitator if necessary
- Information about the opportunity to be assessed for placement
- Information about all available choices
- Information on the obstacles/barriers involved in choosing to move to less restrictive setting in the community
- Information on the timeline for implementation of potential plans and outcomes
- Information should be readily available, linguistically and cognitively appropriate
- Information on how to access the system for assessment
- Information should be provided on a voluntary basis and kept confidential
- Information should be provided on all choices in an understandable format, be simple and concise, and use variable formats including graphics
- Information from participant to be included in process
- Information about any entitlement of services, regardless of availability in community
- Information explaining that an individual will not be locked in a living situation, and can test different options and change his or her mind

- Information providing an example of a person with a similar disability & how they live in community – peer counselor, mentor – individual & family members
- Information on what the consumer's rights are
- Information on the objective or purpose of assessment
- Information on how to access what is available; i.e. who to call; what papers must be completed, etc.
- Information should be available on videotape – for informed choice
- Information on financial benefits available in community situations (SSI, IHHS, etc.)
- Information county staff regarding what they can do
- Information on how to obtain a peer/community advocate or how to be a self advocate

4. What training and background do assessors need?

- The team assessment approach
- Objectivity; impartiality; open-minded, flexible
- Olmstead assessment principles and guidelines
- The philosophy of recovery and a person pursuing their own path
- Familiarity with what is available in the community
- Life quality assessment practices
- Training from various entities – seniors, parents, family members – sensitivity to the issues and points of view of consumers and others involved
- A commitment to community options
- Background in community services
- Background in PT/OT (physical therapy/occupational therapy)
- Sensitivity training
- Training on the tools of assessment
- Resource database
- Cultural competence
- No personal or professional conflict of interest or appearance of conflict
- Ability to recognize depression and other mental health conditions
- Awareness of biases of all sorts, including against persons with disabilities
- Involvement in an independent living center
- perspective that focuses on functional limitations and strengths, not disability
- Broad based knowledge – person & system
- Experience in field for which they are doing assessments
- Familiarity with the individual being assessed (observe him/her over time)
- State & Federal guidelines regarding core competencies and credentials
- In depth knowledge of items in question 3) above
- Superb listener, non-judgmental

- Creative, flexible, common sense
- Belief in value of community
- A “can do”, proactive attitude
- Somebody who knows what its like to live in the community
- Disability/Aging awareness
- Personal experience; assessor could be a person with disabilities
- Knowledge of recovery concepts

5. What information should be collected in an assessment?

- The indivdiuals preferences
- Individual’s risk factors with moving out of institutional care
- What risks are they willing to bear?
- A person’s independent living skills
- Basic personal information, health, transportation, safety, insurance, medical diagnosis, etc.
- Cultural, religious and social background
- Geographic area of choice, neighbors, connections in community, likes and dislikes
- Services needed
- Housing and financial needs
- A lifestyle assessment – because of possible need to move in with housemates or roommates
- The person’s hopes and dreams in six months to a year
- Recreational needs, likes, and preferences
- Ask “how did you get here & what do you think would get you out /keep you out.”
- We can be looking at 2 questionnaires – one who knows what the need is and one who doesn’t
- Familiar services & supports (friends, family, community &advocacy support groups)
- Medical information

6. When and how often should assessments be performed?

Annually

- Ongoing to monthly – so people don’t fall through the cracks
- Upon request or when a change in status occurs
- Formally once; then on a scheduled recurring basis (quarterly, annually, etc.); [big and mini assessments]
- Check in on a routine basis after person moves out of the institution

- When a crisis threatens
- At every hospital admission and discharge
- As people age
- At a transitional age – age 14
- Continuously monitor individuals who are in an institutional setting

7. What happens to assessment data? How is it used? What happens to the evidence of unmet needs, both for the individual and in the aggregate?

- Assessment data should be kept confidential, but consumer should get a copy
- Families & conservators should have access to assessment info as allowed by law
- Aggregate information on all consumers should be available for public use
- Use assessment information to create a transition plan
- Use it to identify unmet needs by comparing assessed needs to available resources.
- Use it for state and community planning
- Consumer should have copies of all information
- Info in aggregate's personal info should be available
- W/unmet need, benefit programmer should go out & assess for local services
- Person should know who has access & sign release to share
- Develop plan to get person into community
- Assessment data should be evaluated & amended if indicated/needed (or disputed)
- Change or enact law to allow family access to data.
- Collect info – identify gaps – report results/document improvement
- Link resources with need
- Report Aggregate data on good programs so they can be replicated

8. What rights do consumers have in the assessment process, and how are they protected and… how are they enforced?

- Right to say no, voluntary
- Right to assessment
- Right to add/remove someone to/from his/her assessment team
- Right to information about process
- Right to information about results
- Grievance and appeals processes

- Right to be reassessed
- Right to tell assessor who not to talk to
- Right to full participation
- Right to fail in a placement and be assessed again
- Right to informed choices
- Access to information in the consumer's file
- Control over what information is shared with others
- Be on waiting lists that move at a reasonable pace
- Individual information not liked by consumer – have it deleted
- Confidentiality
- Able to change mind w/o negative outcome
- Training & bring independent capacities up to par
- Right to have recreational & social needs met
- Discussion w/ person & their dreams for what they may be able to do.
- Right to participate (families and conservators)
- Right to object to assessment if they are competent
- Right to peer and family advocacy & representation
- Right to review assessment in own language or communication device.
- Persons who are underserved need to be routinely re-assessed to obtain their actual choice.

Other Issues

In addition to their responses to the key questions, the Work Group participants made a number of comments on related issues. These were as follows:

- The community needs to be ready for the disability community.
- Emphasize positives. Have a positive frame of reference which characterizes the whole service system
- Assess both before & after movement to a facility
- Require a waiver for institutionalization, but not to stay in the community
- Assessment should be a fluid process because changes come with an individual's growth.
- Assessments should be available quickly, on an interim & crisis basis, if necessary to avoid institutionalization.
- Shouldn't have **only** institutional staff doing assessments, they may not know what's available in the community.
- Assessment should be strength-based, consumer-oriented.
- Reorganize so the state's responsibilities are in one "Department of Assessment." The purpose of this department would be to: 1) to centralize so all assessments will be in one spot, 2) to be the consumer advocateAssessment must be culturally competent

- The Assumption should be Community Placement - Develop new services so that normal process is staying in the community – full integration
- IF WE DEVELOP AN EFFECTIVE FRAMEWORK WHAT'S A REASONABLE TIMEFRAME FOR IMPLEMENTING IT?
- **There needs to be a schedule for implementation. Work group strongly agrees on this final point.**

Olmstead Work Group
Fresno, December 10, 2002

TRANSITION, PLANNING AND DIVERSION

Stakeholder Responses to Key Questions

Each subgroup addressed three issue areas: 1) How to divert consumers from entering institutions; 2) How to transition individuals from institutions to community homes; and 3) What needs to be done to prevent consumers from being re-institutionalized.

For each of these issue areas, the subgroups were asked to identify what processes need to be in place, who should be involved, and what resources are necessary.

Below are the consolidated recommendations from all of the sub-groups, including those who participated via conference call. The recommendations for each of the three issue areas are presented separately.

Questions 1, 2, & 3 – How to divert consumers from entering institutions.

- Assessment needs to be performed before placement into institution; institutions should not be eligible for reimbursement for costs incurred prior to completion of assessment (see Utah and Wisconsin)
- Services should be provided on an ongoing voluntary basis
- Caregivers should be provided with a list of triggers, issues that give a "heads up" that the community placement is in trouble
- People need information on available services and resources regarding community placements, one-stop shopping, presented as a map. Each service provider entity should have a staff person who is well educated in these resources
- Government agency staff adequately staffed regarding Olmstead services and knowledgeable about all other related services
- Doctors, nurses, discharge staff all need to be educated about community placements
- Need to look at shared cost issues
- There need to be half-way houses for people coming out of acute institutions so they don't have to be moved to long-term institutions
- IHSS needs to be set-up prior to discharge from an acute care facility for someone that can be placed in the community

- There should be more prevention services at the community level to keep individuals in community settings. Need to implement AB 953 [set standards for care navigation]
- Need more education about prevention services
- Need 24-hour response care" vs. 24 hr medical care so people can stay at home instead of being placed in an institution
- Look at current structures to include all disabilities. Look at funding streams that are currently divided by type of disability and age; instead, look at by functional ability
- Need to review regulations in light on economic reality, e.g., revisit penalties for being married or living together as domestic partners
- Maximize resources, by helping people in living together who can assist one another
- Multi-disciplinary (continuum of care – involve individuals from different agencies) team approach prior to placement – pre/post assessment and evaluation
- Crisis support services
- Multicultural approach for culturally appropriate svc delivery
- Education of general public on how to live in community as the norm vs. inst care – public service announcements (PSA)
- Universal design for home to be adaptive to needs of the person
- Information should be available to consumers… all interested parties… re: Options /success stories
- Use newsletters & other means of information sharing
- Evaluations need to consider competency/ability of family caregivers
- Assumption should be that non-institutional living options should be considered
- No funding should be provided for institutions until other options have been explored
- An assessment has been done that assumes community placement
- Doctors/med community need to be informed & buy in to non-institutional options
- Chemical dependency intervention
- Temporary institutionalization should include assumption of community placement
- Discharge planning should be more effective and community based. Consumers and family if client agrees
- Individuals knowledgeable about options/resources
- Multi-Disciplinary team including housing, gerontology, medical, advocate, therapies
- Ombudsman
- Reorganize state government so that all social services are in one dept (client chooses social worker)
- All points of entry into LTC should lead to assess & diversion in accord with Olmstead

Questions 4, 5 & 6 – How to transition individuals from institutions to community homes.

- Assessment should include client, family, doctor, community placement staff, institution staff; should address individualized services
- Early planning; list of real needs of individual to stay in home; education and clarification of process to actually move into community setting
- Use the knowledge of the hospital staff
- Implement AB 499 [Assisted Living Demonstration]
- Address services needed other than medical, e.g., transportation, equipment to be needed at home
- Need to be aware of use of language, e.g., process should be consumer "controlled", not just consumer directed". Consumer should drive the process and make decisions.
- In all recommendations, need data on who needs services at state and county level
- Cultural competency principles include age, ethnicity, gender, sexual preference
- Modify State Medicaid plan. Instead of expanding services by expanding waiver slots, make it part of the Medicaid plan itself.
- Redefine definition of medical necessity to allow for coverage of Assistive technology, e.g., for people who are transitioning or at imminent risk of going into an institution, e.g., stair glides. (Stair glides were allowed in one decision; should be included in the plan.
- Review durable medical equipment list with consumer participation
- Need durable equipment in place before discharge. Evaluate the home for needed equipment with the person present.
- Review state special circumstances grant: dollars for rent, pots and pans, and move in type expenses
- Modify NF waiver
- Develop "mega team" – people knowledgeable of all services and how to be apply for services (transportation, HUD, independent living, IHSS) and be advocates
- Resources & needs into statewide database (info avail at time it is needed)
- For consumers provide information; provide aggregate data for planning
- Sufficient waiver services, slots & funding for all who are eligible
- Chemical dependency intervention
- Make available temp placements in institutions to find community options
- Independent assessment to avoid conflict of interest
- As easy to "get out" as to "get in"
- OT & AT assessment
- Assistance with transition (to individual for such things as move-in costs, home mod), funding, waivers, collaborations. Loans, etc.
- Avail CMS funds for transition – state should seek security deposits (pre-funding)

- Money should follow person (all disabilities)
- Cash and counseling (consumers decide what services to purchase)
- Guaranteed access for advocates & others to educate clients/consumers in institutions of community options
- Funding should recognize the length of time required for transition
- Caseworkers/staff should understand & have empathy for clients/consumers.
- No county financial incentive for alt to nursing home placements
- Public guardian should be prevented from selling homes of individuals they oversee
- Eliminate disincentives for shared living & shared support services in all programs
- People involved in the transition process should be consumers & peers; the family, if the individual wishes, and the assessment team
- Guardians & conservators actions should be consistent with Olmstead principals
- State & local officials should be involved to access CMS funds, and facilitate regional task forces on unmet needs
- Prohibit “cold calling” – provide orientation period for person
- Provide a strong support system – encouragement from hosp MDT (multi-disciplinary team) family, friends, to help with connections once in community
- Provide access to inform to be released once – not multiple times
- Housing – taking advantage of subsidized programs by using state funds for this – can get more services in home setting
- Have trained individuals who go into home assessing individual
- Focus on hopes/dreams of person & not limitations – while someone who has been thru process/realities – peer counseling
- Provides services needed to ensure successful transition
- Provide safeguards in community – oversight re: quality of care in community – should be similar to monitoring requirements established in institutional Settings
- Safeguards should be focused on community setting – appropriate for the setting of person – make standards applicable to community setting – “common sense applicability”– can be difficult to establish
- General registry of available services for all – for example – Public Authority Consumer Registry for Services
- Payor services
- Formal organization of non-traditional providers/churches, families, caregivers
- Need: intensive 24/7 supports on move to community. Person initiates.

Questions 7, 8 & 9 – How to prevent consumers from being re-institutionalized.

- Need state support for integration and coordination of long-term services; use AB 1040
- Conduct home visits shortly after placement in community; routinely thereafter until person is comfortable with home setting
- Make available physical therapy in home
- All transition plans need elements regarding on-going support.
- People that are at risk need services on demand
- Mandate annual training on current knowledge and resources for all staff involved in transition and deflection
- Provide continuum of care as long as person is in community
- Staff visit consumer, may include other folks placed and living in community
- Fitness and therapy services made available
- Level of Services must meet level of need
- More advocacy to override institution interest
- Timely follow-up & problem resolution
- Inform consumer choice and caregiver knowledge of options & training for both.
- Real time information focused on availability of local services
- - Statewide 211 # -
- Caregiver registry on-line
- On-call caregiver services for short term fill-in
- Best practices (emergency services)
- Organize on-call workers for back-up rapid response
- Rapid response, e.g., emergency back-up, if caregiver doesn't arrive
- Interventions (jobs, housing, Sect 8, SSI, IHSS, etc.) for holding supports during hospitalization
- Coordinate programs & stabilize funding (accountability)
- Drug intervention (staff/clients)
- Increase trained personnel, e.g., social workers and other staff, peer providers, students
- Develop career paths for workers from entry level to professional staff
- Rededicate resources for institutional care to community living
- Training of consumers in skills, transition services
- Need to address Financial aspects (as in planning, managing own finances)
- Need to educate the community at large (especially Police and Fire), need public service announcements
- Transportation, alternative formats of language/communication
- Case management, PT, exercise
- Non-traditional supports – peer groups, volunteer services, friends – may get more information from person on how they are doing – person may be afraid to tell pd svc entities for fear of rehospitalization

- Individual / family counseling
- Need “neighborhood watch” models in communities – limit those taking advantage of person
- request re-evaluators as needed – not just @ prescribed timelines
- refresher courses for info on available services – people forgetful: attend presentation to ask questions – education / training courses for consumers ongoing basis
- Establish simple list of rights – readable format – to be used by evaluator of person also.
- Need a crisis team plus other resources such as a hotline
- Train cross-disciplinary advocates
- Persons who should be involved include: Multidisciplinary team; the individual consumer; family; faith community; doctors; law enforcement; nurses; social workers; resources from the institution who may also have knowledge of person/needs; friends; caregivers; treatment team members
- Train care providers based on need of person
- Respite for caregivers – VERY MUCH NEEDED

Olmstead Work Group Meeting

Los Angeles, January 10, 2003

Stakeholder Responses to Key Questions

Transportation and Housing

HOUSING ISSUES:

- Listings are
  - Limited
  - Incomplete
  - Unavailable

- Local Solution needed for
  - Info referrals – updated data bases
  - Low vacancy rates
  - Develop more units
  - Homeownership responsibilities lack of knowledge
  - Appropriate info support

- Universal design
  - Model ordinance – 2787
  - Need widespread implementation
  - Need more affordable & accessible units for ALL incomes
  - Mixed populations
  - "Screening" can be barrier e.g., large deposits, credit history
  - Need incentives for land lords to accept section 8 & other subsidies
  - Need preservation of existing subsidized units
    - change stigma
  - Need new ownership models
    - e.g., rent to own
  - Need incentives for affordable housing development, e.g., tax incentives, subsidies
  - Need supplemental programs
    - e.g., aid for deposits, moving costs

- PRIVATE MARKET
  - Is not accessible
  - There are no incentives for modifications

- NEW STATE LEGISLATION NEEDED
  - Support services to age in place

- In-home support services to include moderate incomes

- INCENTIVES for private mkt.
  - Shared accountability
  - Cut development time
  - Sale of city-owned property for certain housing types
  - Federal subsidies to lowest incomes (e.g., Sec. 8, TANF) but state reluctant to provide tenant-based rental assistance – TBRA
  - Get more Federal TBRA
  - Get more state dollars out to ensure permanent affordability & build up stock

HOUSING RECOMMENDATIONS

- Better information and referrals
  - Need more Local responsibility
  - Need listings to state "accessible" or convertible

- Universal design must address **visit**ablility
- Increase total housing stock
- No new bureaucracies to accomplish recommendations, use existing programs
- Housing element to include data base of affordable & accessible units
- Non-profit access to waiver programs for housing
- Expand In-home support services use for in-home modifications and maintenance
- Expand eligibility for in-home support services (wider income range)
- Incentivize private market to build affordable accessible housing
- Every county to have local housing coalition
- Regional centers should develop affordable housing for their clients
- State dollars only to accessible units
- Rent ought to be capped at 30% of personal income
- Change regional centers strategy to maintain units as permanent affordability without concentration /"ghettoizing" disabled population
- Accessible, affordable & integrated subsidized housing

TRANSPORTATION ISSUES

-- Fixed route, Paratransit Demand

- Insufficient, doesn't run long enough, doesn't go far enough, unreliable, not integrated, costs too much, paratransit not user friendly
- Not enough people with disabilities are taught how to drive
- Advance notice is required, that is not reasonable
- Too many buses have lifts that are prone to breaking down

Transportation Recommendations

- All buses need to have low-floor vs. lifts
- Expanded operation time
- Expanded use of “smart cards”
- Funding for modification of vehicles
- Access for private vehicles e.g., have certain percentage of public fleets be accessible
- Train/educate on how to use public transportation (IHSS could sponsor) e.g., Sacramento’s Regional Transit model
- State monitor transit system for Unruh (ADA) violations

Community Living Arrangements and In-Home Supports

What are the Info and Referral problems for Comm. Livings in-home supports

- Difficulty in finding needed information.
- Delays in provider payment and paperwork.
- Bad image of providers instills fear in using program.
- Misconception re need for services.

What Information and Referral recommendations should be made?

- Single source of information/resource and referral. Web-based eligibility (Coordinate with 211 – one phone number across state)

IHSS

- Newsletters as information. Source
- Utilize public court records.
- Utilize mass media to outreach (begin in March 03)
- Information in multiple languages (post in apartments, etc.)
- Expand CA CARES – across state – links to local/reg services
  - Key words
  - Cross ref.
- Make info on WEB available to those without WEB access.

What problems exist regarding the available types and modes of services? For community living? For in-home supports?

- Expand to include home maintenance and repair.
- Weatherization
- Problems getting "pay" for multiple providers and flexibility of hours – respite.
- Assessment should reflect medical need – not budget.
- Insufficient providers, services, wages.
- Individuals not eligible for IHSS need IHSS-like services.
- Non-parity of wages
- Misconception that Dev. Center is necessarily more costly than community care.
- Contrary – others voiced statistics that community care is less.

What recommendations for Modes & Types of Services?

- Equal pay for equal work – parity among providers
- IHSS – Medical professionals should make recommendations based on need (not Social Workers)
- IHSS – Utilize state hearings
- Provide subsidy or tax break for non-IHSS needs.
- Improve and increase training.

What are the eligibility problems?

- Determining eligibility for advance pay in IHSS
- Nuance of language can determine eligibility, but should not
- Eligibility for supported living based on verbal choice (traditional communication), should include other family members.
- Definition of “able” and “available” spouse is a problem.
- Denial of program eligibility when Income is slightly above eligibility standard
- If adult child living in home get less hours
- Less service hours are granted when recipients live in a shared-living arrangement
- Frail spouse with dementia spouse - Expectations that a spouse is “able and available” to provide services.
- Training for Eligibility Workers.

What eligibility recommendations are needed?

- Eligibility. should not rely on traditional communication only for ESL but also for recipients who cannot communicate verbally or in writing.
- Choice should remain for consumer and conservator.
- Make info available on all options even in other geographical areas.
- Improve training for eligibility workers.
- Smaller caseloads.
- IHSS Contract Workers - Make it easier for advance pay eligibility or return to community based/agency assistance. Use community-based organizations/non-profits as an intermediary to receive “advance pay checks” on behalf of a recipient.
- Provide accommodation to allow clients to “sign” checks to allow “Advance Pay” for recipients who do not have the ability to write.
- Redesign IHSS computer payment system.
- Remove cap on assessment hours.
- Complete a time study on hours needed for services.
- Expand IHSS eligibility for recipients with mental health needs.
- Eliminate artificial distinctions for eligibility for services. (This issue was raised as a result of stakeholder discussions that, even though you had a need for a particular service and this service may be provided to an individual with the same condition as you have, you could not receive it because you were not a client/recipient of a particular program.)

What are the problems with the current quantity of community living services? In-home support services?

- Not enough services
- Low wages
- Need financial management services
- Medical appointment accompaniment should include Dr’s visit time
- Lack of affordable IHSS like services

- Waiting lists (MSSP/waivers)
- Statewide nursing shortage
- Lack of bilingual communication (Address other communication barriers besides ESL recipients. For instance, recipients who are illiterate or non-verbally communicative.
- Lack of services to teach clients how to live in community (client choice)
- Shortage of housing & services.
- Inappropriate incarceration

What recommendations are needed regarding quantity of services?

- Higher wages
- Services to meet needs
- Parity in wages
- Household/financial management services based on disability, language & literacy barriers
- More Medi-CAL providers
- Parity in reimbursement for Medi-CAL providers
- Advocate for increased federal services
- Increase waiver slots
- Investigate reason for waiting list/unfilled slots

What are the major community living funding problems? IHSS funding problems?

- COMMUNITY LIVING
- This area cut first in fiscally tight times
- IHSS

Community living funding recommendations – In-home support

- Funding follows person with need (begin Aug. ’03)
- Access more fed. Medi-CAL funds & keep $ in system.
- Funding supporting developmental centers could support individuals in community
- The opposite view to the above was also expressed
- Expand support of volunteer organizations to leverage funds
- When DC property is sold - $ stay in system

Day Activities, Recreation, Education, Employment, Leisure

- All LTC/ Support programs should support out-of-home activities (social, employment, etc.)
- Senior companion-type program should be available to non-seniors who need it
- Consumers need to be the focus of services & supports
- Need a clearinghouse for services that consumers can access (consider the use of technology)
- Establish internet-based day activities and peer group/interaction
- Assess whether programs/services actually contribute to the consumers' meeting their goals
- Consumer as "captain of the ship" – how do we make that happen? Implement a "self-determination" program model
- Incorporate consumer satisfaction measures into all services
- Service providers need education on facilitating individual's choices
- Adopt real choices model
- I & R services need handoffs, not punts from agency to agency
- Various social services for persons with long-term care needs need to be consolidated into a LTC department
- Providers need to be clear on their own rules
- Make Ticket to Work a viable option in California
- Have consumers train providers on listening and hearing them
- Living wages/benefits for direct-care workers
- Jobs need to fit the worker rather than vice-versa – flexible
- Job supports need to be clearly defined
- Adopt "just one break" jobs model. Provide tax incentives to employers
- Services should follow the consumer wherever they go
- Restrict tax burdens and share of costs for persons with disabilities to allow them sufficient income to maintain a community based life
- Day programs need to provide non-medical services – need to establish a category of services for community based living
- Develop a community living model that provides for service categories that support the model
- Reserve a portion of benefits for leisure/recreation
- Educate natural supports (i.e., family members, friends, churches, etc.) on the consumer's potential and needs.
- Educate employers on disability awareness
- Conduct a statewide employer campaign on employment of persons with disabilities
- Educate the public on disability policy

Crisis Services, Services Coordination, Advocacy

1. Info & Referral Problems
   - When people don't qualify, how do we refer?
   - Develop for medical community re: what is avail for persons with disabilities
   - All persons in the medical establishment need to be educated
   - Information & Referral (I & R) is not provided consistently around the State
   - Discharge nurses are too overwhelmed
   - People are discharged too quickly
   - Lack of uniform case mgmt except for DD
   - Institution-based persons can't access for community living – lack of knowledge, different incentives
   - Difficult to refer if there are no providers
   - Confusing process – need for a central Information & Referral source (I & R)
   - Diversity and language barriers need to be taken into account now. Plan for growth in this issue.

2. Info & Referral – Recommendations
   - Advocacy for those in institutions is hindered by opposing $ incentives
   - Bring knowledge into the institution from the community; best if they have a partner in the institution.
   - Develop online I & R that is regularly updated in every county
   - Need for I & R re: a source of emergency aid
   - Fire departments, other emergency responders need to know the information – or who to contact for it
   - Existing web based systems need improvement
   - Hospital discharge planners must contact 3 service providers – RULE
   - Info-line and other I & R sources need to be accountable
   - Train the consumer to obtain the I & R
   - I & R sources need better training
   - Need published hard copy information in each county

3. Types & Modes of Service – Problems
   - Lack of crisis case mgmt (short term service)
   - Have community care available in hospital
   - Have an ombudsman established to assist individuals who have been referred to a nursing home. Whoever makes the referral must contact an ombudsman
   - Non-verbal persons must have an ombudsman if recommended for placement
   - Have a system of emergency attendant care

- Open the attendant registry (In Home Supportive Services or IHSS) to everyone
- Provide accessible emergency shelters or transitional homes
- Establish crisis teams in police, fire, etc to respond. Mobile team links this to crisis center where more in-depth evaluation can occur
- Provide private homes to serve as emergency crisis shelters
- Educate people re: availability of Adult Protective Services (APS) to assist in crisis
- '911' registries should be established

4. Eligibility – Problems
   - If in crisis, a person should have presumed eligibility – for certain basic crisis services and a thorough evaluation
   - Increase slots for linkages and Medi-Cal Multipurpose Senior Services Program (MSSP)
   - Expand eligibility – funding stream limitations
   - Time limits, waiting periods for services
   - Block grant programs to eliminate stove pipes and simplify admin – and allow for a non-profit arm to solicit funding for non-eligible
   - Provide a waiver of eligibility limitations in a facility where a program provides services for one population (e.g. seniors) but others need the services (e.g. meals) in an emergency

5. Funding – problems
   - Increase the funding avail for the MSSP to more fully meet needs while maintaining cost neutrality
   - Plow back additional Federal Financial Participation resulting from increased waiver billings into programs, should not go to the state general find
   - Solicit private funds to match Federal Financial Participation
   - Investigate all crisis, case management and advocacy programs to see if they can funded via Medicaid
   - Survey and educate the population re: cost of avail services
   - System to allow state the bill 3rd parties for emergency period care if they have insurance
   - Access Title III-E (of the Older Americans Act) funding for caregivers of families in crisis
   - Provide more flexibility in the use of funds for emergency services
   - Categorical funding limitations

Medical Services and Assistive Technology

- Knowledge is power
- Develop method of educating appropriate individuals on available services in comm. & holding them accountable
- Develop process for data collection to assess gaps/availability of services
- Develop interagency communication processes for information sharing
- Develop statewide network of info-include generalist & specialist in needed areas in accessible formats for all written, oral, computer based, Braille – professional & lay level
- Improve into sharing on use of hospice
- Access service in facility based settings regardless of association w/facility

1. Info & Referral Problems R/T Med. Services & Assistive Technology (AT)?

    a. Med SVC – Difficult to work through maze – what is covered, what is not? Lack of knowledge of resources

- Attitude counties may have w/individuals who come in for services – lack of knowledge by workers & how to deal w/problems brought to their attention incl. Facilities, nursing homes
- Question if services are being provided in equitable, non-discriminatory manner.
- Knowledge inadequacies
- Assumption of delivery system based on self advocacy
- Inability of certain caregivers to assist individuals w/medical referrals: inappropriate information provided to MD thus inappropriate or poor F/u/referrals

1b. Recommendations for Info & Referral

1. Statewide network of information – generalist & specialist on available resources.

    - Facility & community-based for all to access
    - Information in accessible formats (written, pictures, computer, Braille, oral)-diverse, multicultural professional level, lay level
    - Information in accessible areas – local supermarket, public library, public service announcement, MD offices.

2. Improved/better communication among provider, community care provider, facility
3. Interagency collaboration needs to be increased

4. Consumer/family information sharing
5. Access/info on hospice services.

2a. Existing problems with available types & modes of medical services & Assistive Technology?
-Gaps in services – gaps in availability
-Available services are not broad enough

There is a Lack of:

1. Dental services 0 widely available for individuals. Especially CDD needs
2. Respite
3. Behavior modification
4. Shoes
5. Wheelchairs
6. Pharmaceuticals
7. Nursing
8. Unlicensed caregivers – any person providing hands-on care
9. Assistive communication devices

2b. Recommendations for types & modes of service.
-Assess available services & determine what is available & appropriate expenditures of services

3a. What are eligibility problems?

-Problems at county level & why people are not made eligible for services – counties not knowledgeable in services, programs.

-Inconsistent information provided by case workers, IHSS svc workers, nursing facilities, acute care settings.

-Providers not knowledgeable in available services

-Lack of knowledge on policies regulations, laws, establishment of "underground rules"

3b. <u>What are eligibility recommendations?</u>

Training, accountability of info provided

4a. <u>Problems w/current quantity of medical services & Assistive Technology (AT)?</u>

-CA residents do not have access of specialized services that are found in any facility that has expertise in area of needed services.

-No availability of service providers: availability of services.

-Lack of providers to accepting funding services.

4b. Recommendations for quantity of services?

-CA residents need to be able to access facility services on an outpatient basis due to expertise in the given facility regardless of any assoc w/the facility

5a. Major funding problems for medical services & AT?

Poor data collection: Do not know where gaps exist

5b. Recommendations for funding

-Data collection to determine needs, duplication of services.

Phone Group Discussion

HOUSING & TRANSPORTATION:

Information and Referral Recommendations:

- Information needs to be available when people need it. Counties should commit to issue resource document with service and cost information annually.
- Make criteria for eligibility known. Outreach to people who don't know they are eligible
- Metropolitan Transportation Authority has lots of information and material. Should be made known to all Olmstead community
- Educate people about tenant rights

Types and Modes of Service:

Transportation:

- Develop peer training for people to use public transportation. Santa Barbara has such a model.
- Mandate for connectivity across district lines, especially in rural areas.
- Need staff that are well trained/expert in transportation rights. Maybe develop an internet service
- Need same day services for transportation
- More timely appointments for transportation; reduce the window of time for an appointment, down from an hour and a half.
- Coordinate Regional Planning and connectivity among transportation authorities and transportation providers. Coordination meetings should be open and advertised to Olmstead Community
- Need to enforce accessibility transportation laws.
- All lifts should be rated to a minimum of 1000 lbs

Housing:

- Re: Prop 46 – make sure that people with disabilities have access to all Prop 46 housing.
- Mandate that Regional Centers have housing expert on staff
- Need staff sensitivity training. Provide sensitivity training for HUD and property managers, especially around accessibility. [Caregivers cannot always get into a place because facility is locked after certain hours.]
- Housing needs to be near transportation and services.
- Housing needs to be subsidized so there is enough income after paying rent to cover other costs
- Provide living skills training, including taking medications and budgeting
- Service plans should be required to include 1) person's housing goals, 2) resources needed to achieve housing goals & 3) person's crisis plan, e.g., Wellness and Recovery action Plan (WRAP)

- Offer a way for consumers to share housing vouchers, e.g., Section 8, so they can share housing. Merge senior and disabled housing, e.g., in trailer parks
- Develop housing that is accessible to people with environmental sensitivity. Involve E Health Network in this issue.
- Increase the level of care permitted in assisted HUD housing so people don't have to move
- Develop and enforce standards for inclusivity in privately owned homes
- Need to assure compliance with HUD rules.
- Develop long-term plan for inventory to meet need for housing
- Bring disability and senior communities together with housing developers to plan how to meet housing needs, redevelopment agencies, housing authorities
- Hire people with disabilities as consultants to public agencies developing accessible housing
- Accessibility housing isn't accessible for new equipment
- Provide incentives to non low-income landlords to take people with disabilities as tenants
- Develop housing units with room for live-in attendants and new equipment.
- Require accessibility door openers

Quantity

Transportation:

- More transportation: Long waiting times for transportation. Not all busses meet accessibility needs. Need more paratransit in rural areas and longer hours of service.
- More types of transportation: Need more electric busses

Housing:

- Accessible housing for higher income people who don't qualify for low-income accessible housing.
- More housing subsidy vouchers for people transitioning out of nursing homes – make it easier to get out
- Increase among of accessible and affordable housing in consolidated plans
- State Legislature to avail themselves of strong new legislation that will lay out "affordable" "accessible" housing with "visitability".
- New funding due to housing legislation passed last year should be ear-marked for Olmstead

Eligibility:

- Need systemic revamp of requirements
- Community should be involved in planning of functional testing (if we don't eliminate it.)

Funding:
Transportation:

- Reinstate special circumstances fund with a pot for transportation
- Fund study of counties paratransit to see if the staff and service are respectful and responsive to people

Housing:

- Increase the $11 million in Prop 46 allocated to persons with disabilities
- Maintain escrow fund for up to 180 days before discharge
- Create a dedicated fund for housing rehabilitation
- Year-by-year funding for housing stock
- Prohibit local option for builders to "buy out" of providing affordable housing units. Results in jurisdictions getting behind in their affordable housing goals

Other:

- State negotiate with feds to reduce waiting lists

COMMUNITY LIVING:

Information and Referral:

- Clearinghouses for creative living situations
- Registry for IHHS services – including people with disabilities

Types and Modes of Service:

- Before people are discharged, they need to have developed a personal support system in the community – need social contacts and places to go.
- Train people in community living. Registry of trainers to start while people are still in institution
- Need creative living arrangements – shared staff and housing
- Registry of people with developmental disabilities for mentorship program for people in hospital – some who lives in the area where someone will move.
- Create stable housing – rental and home ownership
- Builders/Designers visit units blindfolded on crutches in wheelchairs after units are built so they can understand the difficulties of people with physical disabilities
- Need fully accessible recreation facilities so that activities can be inclusive
- IHSS workers should n screened for alcohol and drug and mental health problems. Criminal background checks should be optional
- Increase IHHS maximum hours
- Recognize time between teaching and learning. Don't give disincentives for person being too quick.
- Workers need to be respectful of nontraditional relationships.

Eligibility:

- Less complicated need assessment for IHSS
- Revise co-pay ceiling and increase more gradually. Adjust for regional differences in cost of living. Buy-in/share of cost for consumers needs to make more accessible for non- income eligible for IHSS
- Regulations shouldn't punish nontraditional relationships. Get rid of marriage penalty

Funding:

- SSI recipients should be eligible for food stamps

CRISIS SERVICES, SERVICE COORDINATION AND ADVOCACY:

Information and Referral:

- Simplification of information. Provide survival kits of information. What services are there and do you get them. Map how services link to one another

Types and Modes of Service:

- Drop in centers
- Telephone access—because of poor transportation
- Peer counseling
- Training and accountability of staff
- Data collection of quantity and quality of services
- Single Point of Entry for all services. Linking among services.
- Provide consumer/family/attendant-friendly services
- Programs must accept training by consumers/family members when people are getting ready for the transition
- Flexibility beyond N station critical (???)
- Provide short stay, multidisciplinary staff quick crisis treatment, so people don't lose housing or community services while in crisis
- Provide "service first", and then figure out who pays
- Focus on early detection and prevention
- Develop multi-agency crisis intervention teams
- Escort service for people in crisis, including peer support
- Repeal AB 1421 – there is no room for involuntary treatment
- Every state funded case management program accompanied by a consumer directed form of service coordination
- Monitor Board and Care homes for people with mental illness – need to follow licensing guidelines.

Quantity:

- Expand hours of service
- Need more crisis services

Eligibility:

- No age or relationship barriers. Keep couples together.
- Program flexibility for affordable buy-in for people who are not income eligible; instead of having to lose assets to become eligible.
- Consistency of eligibility criteria
- Eliminate Age criteria for meals on wheels
- Don't penalize for child support.
- Dollar cut off for eligibility for services has to reflect economic realities of are in which you live

Funding:

- Provide incentives for attendants for work in rural areas. Provide attendant trainings in rural areas
- Provide dollar incentives for joint ventures between/among agencies serving the same population, e.g., people with developmental disability and mental illness.
- DMH explore funding warm lines as a crisis prevention effort
- Explore funding network of consumer-run centers in each county
- State mandate for funding and monitoring of crisis services

OTHER RECOMMENDATIONS:

Suggestions for Olmstead planning:

- Involve consumers in developing waiver programs
- Level playing field for consumers. Mutual aid for commonality of programs
- Don't exclude smaller nonprofits because they may work more with special populations
- Local plans among agencies
- Counties staff cooperative/collaborative relationships for local Olmstead
- Consumers must participate in federal waiver plans
- Assess services providers in rural counties; identify and prose solutions to meet gaps. Housing

Rural recommendations:

- Assess current community based services and organizations in rural counties to make recommendations for meeting gaps. Survey need for fuel and food. Identify people to work cooperatively. Include Housing Authority in planning.
- Eliminate Age criteria for meals on wheels

Olmstead Work Group Meeting
Oakland, January 22, 2003

QUALITY ASSURANCE and ISSUES NOT PREVIOUSLY ADDRESSED

Stakeholder Comments to Key Questions

QA GOALS

Assessment –

1. IHSS Training must be given to doctors and social workers so they are more qualified to determine assessment of hours
2. Doctors should conduct the first assessment and be the one who does the final sign off
3. Social workers should ensure the correct policies/directives are in force
4. Insure consumer has direct involvement. Persons doing assessments must communicate directly with the person receiving service instead of only asking an aid or social worker
5. Ensure that the consumer has a mentor if needed, and is educated in a consumer-friendly way; ensure that the consumer's choice is truly informed
6. Ensure quality by peers and community t4eams through a sampling process
7. Every assessment include a friend/ or someone the individual being assessed can trust
8. Peers can and should do assessments
9. Individual assessments should be given to the person and their advocate
10. Comprehensive, collaborative w/balance between consumer, advocates and the independent evaluation
11. Evaluate person once in community, revise plan if needed: ongoing + status
12. Measure assessment in inst. vs. assessment in community: variances
13. Appropriate timelines for assessment completion
14. Assessment should be available when needed, including during crisis
15. Assessment should determine what services are necessary not document a record of deficit (i.e. what the person needs, NOT what the person needs as modified by the service set that is presently available.)
16. Measure quality of assessors – they should have appropriate skills and no conflicts of interest
17. Quality of assessment should be assessed at all stages – did the consumer have REAL choices – including choice of assessors
18. Consumer should have last word and make the final decision

19. Need to include all of the assessment parameter agreed upon at the San Diego Work Group meeting

Transition/Diversion –

1. Conduct a complete inventory of available beds, Medi-Cal and private pay, and determine what criteria is used to allocate to Medi-Cal or private pay.
2. Care plan must be developed and given to the person and their advocate
3. Shared agreed upon assessment with family, someone of choice
4. Educate the public about benefits of community living and provide equal time on outreach
5. Incorporate consumer satisfaction & consumer choice
6. Use of professional organizations: oversight, guide on standards
7. Provider/consumer satisfaction survey on delivery/lack of delivery of services.
8. Include monitoring and accountability of State departments involved in the plan, e.g., Mental Health Planning Council

Community Capacity --

1. Increase capacity to divert from re-institutionalization
   - Process should be devoid of age/abilities of individual: look to @ need and capabilities
2. Focus should not be on institutional placement - community placement should be first
3. Measure how well we meet the desires of consumer; moving toward ultimate goal & stated desire

POLICIES AND DIRECTIVES TO BE IN PLACE TO ENSURE QUALITY

Assessment –

1. Care plans/case assessments must be followed-up and reviewed by "team" to help ensure compliance (client, peer, and doctor).
2. Plan of care must be revised regularly and modified as necessary to ensure outcomes are being achieved
3. Assessment reviews must be at the convenience of person requiring service.
4. Persons doing the assessments should be given a financial incentive to give quality assessments.
5. Develop and measure health status outcomes: use nationally based models –consumer based
   - if assessment is not appropriate, evaluate process
   - consumer satisfaction should not be only measure of quality
6. Cultural competence/diversity recognized
7. Outcome based information to incorporate some level of self risk of person and choices made

- QA systems should incorporate outcomes but if not achieved, system should not be identified as a failure
- incorporate supports available to person

8. Done annually w/quarterly assessment/updates + emergency care plan (CP) meeting can be called as needed by consumer, provider
9. Coercion – AB 1421 mandates involuntary outpatient treatment – clients should truly be in charge of their own treatment
10. Teams for assessment should include trained clients/peers
11. There should be a State policy of entitlement to: transition and assessment services; community placement should be assumed unless otherwise determined
12. Pass a law to require reassessment post-placement by both Social Services and Rehabilitation agencies

Transition/Diversion –

1. Training must be provided to people in institutions to prepare them for the community
1. No one from within a facility should perform independent living training.
2. Follow up within 72 hours of transition to ensure the person is doing well.
3. Case managers must do follow up/review cases in 45 to 60 day intervals to ensure that training elements are practiced and to see how well the individual is transitioning
4. Consider different transitions/diversion needs for individual living in urban vs. rural areas
5. Establish a call in number/ hotline for newly transitioned people
6. Everyone must have a follow up plan.
7. Require provider training, i.e., require a certain number of continuing education units annually. This should apply to Discharge planners, public educators, and clinic and hospital staff
8. Ongoing, unobtrusive evaluation (monitoring) – constitutional rights/issues to be addressed
    - Education of individuals in this area
    - Did this assist in keeping person in or out of inst. setting
    - Keep in mind cognitive ability w/choices made – along w/input from caregivers/decision makers
9. Advocates and case managers need to communicate to better serve consumers especially in regards to placement decisions
10. There should be measurable quality standards and goals required of providers, agencies and clients, and these should occur at all levels – local, regional, and state.
11. State should count the number of consumers diverted, the number placed, how long it took, and set goals and target dates.

Community Capacity --

1. There should be assurances that needs are being met in timely manner
2. Communities/peer group should perform evaluations
3. Some type of enforcement for QA activities
   - Funding or citations as appropriate
   - Measure against goals
   - Example random sampling of providers by individuals who use services.
4. Confidentiality requirements make it hard for clients to determine the suitability of caregivers and clients find it too expense to do background checks of workers; safety should be a major concern; consumer choice should be the deciding factor
5. Rigid rules about who can provide supports in community setting should be reviewed & replaced with consumer choice measures
6. Board and Care and unlicensed homes need to be accountable to state/federal rules and regulations; if not, placements should not occur – there needs to be recourse available for clients in such homes who receive inappropriate treatment; mental disorders need to be considered besides physical disabilities.
7. Ombudsman services should be available for those in Board and Care placements
8. A Central Office of Quality Assurance should look at all services – the quality assurance assessor could be an advocate for the clients

TO WHOM ARE PROVIDERS ACCOUNTABLE?

The following apply to all categories: Assessment, Transition/Diversion, and Service Capacity

Those doing Assessment must be accountable to:

1. To State department as appropriate
2. To case managers
3. To consumers
4. To appropriate county department or Regional Center depending on who is doing the assessment
5. To the funding source i.e. county, state, federal (May all be managed by the county)
6. Require independent outside audits (like NCQA or JCAHCO) and/or multi disciplinary provider team, quarterly
7. Ensure the consumer is a leading participant of the audit process.
8. If JCAHCO does assessment audits they need to upgrade their standards and strengthen their protocols.
9. Training must be mandated for all auditors, licensing agencies, and those who perform or manage any quality assurance functions.
10. Must be able to do unscheduled, unannounced visits/audits
11. Self help group involvement/client focused/client run groups to be involved

12. Consumer (paid) as part of evaluation process
13. Uniting of health/social services for accountability – collaborative efforts
14. Beyond direct service, the state is accountable to at every level to determine if more people out of institutions and living a better quality of life
15. Accountability needs to equal consequence and clients should have to be part of developing the consequence system (see federal Home and Community Based Waivers for accountability requirements.)

INFORMATION THAT SHOULD BE COLLECTED

Assessment –

Collect:

1. 1st hand info from person receiving services
2. Integrated data from case records
3. Data on best practices
4. Information on medications and diet
5. Information on mental health and effect of medications
6. Audit information
7. Periodically survey 100% of patients
   - Provide assistance if needed
   - Ensure anonymity (no name, room number, etc.)
   - Consider survey designed by consumers
8. Health status – use of health delivery models – keep balance w/consumer choice/self determination
9. Measure the percentage of assessed clients who move to the community

Transition/Diversion –

1. Conduct a complete inventory of facilities and available beds, Medi-Cal and private pay. Determine what criteria are used to allocate to Medi-Cal or private pay beds.
2. Track discharge, where the individual is going, and movement back and forth
3. Track facility to facility moves (numbers of transfers)
4. Track facility to home and then back to facility
5. Track deaths including cause of death by facility
6. Track number of training sessions conducted with persons in institutions and number participants receiving training

Collect all information listed in Element Five of the NAPAS Template

Measure how much savings are being generated by people being in community, including older population, vs. living in institutions

7. Track best practices
8. Data on people going in + out of institutions
10. Comparative data by responsible area
9. Baseline 2003 data + track from here – all areas
10. Aggregate data from all private institutions on who goes in, who comes out, and who gets diverted

Community Service Capacity --

1. Trend data on assessment + delivery of services.
2. Community database of resources w/ongoing updates
   - Can determine what is lacking/improving
3. Number of delayed discharges or admissions due to pack of community resources
4. Data on unmet needs Client satisfaction surveys are insufficient measures – responders fear reprisal; they feel a need to please providers; more objective measures of satisfaction are necessary like personal outcomes measurement
5. Collect information that identifies good models and best practices for replication

HOW INFORMATION SHOULD BE USED

The following apply to all categories: Assessment, Transition/Diversion, and Service Capacity.

1. Assessment information collected should be signed off by consumer
2. Data should be used to reveal the quality of the plan of care
3. Information should be used to support appeals and grievances
4. Data should be reviewed annually to analyze for trends and patterns by two review bodies:
   - By an outside source
   - By state departments as appropriate
5. Data should go to consumer and their family to enhance their ability to choose
6. Information collected should be made available to the public in simple terms
7. Information should be available for patient assessment at all facilities
8. Develop a point system or star system like in the “auto club guides” to show rating and give credit for good programs
9. Use data to reward, to give financial incentives
10. Mechanism to reward good practices vs. poor

11. Make continual improvement in all areas – what works what does not
12. Use data to hold state accountable for implementing commitments under Olmstead as well as those who advocate for these tenets.
13. Evaluate effectiveness of institutional vs. community assessment + achieved goals/outcomes
14. Publish results and reward positive outcomes continuously
15. Information needs to be accumulated in one place with confidentiality safeguards with feedback loops built in to local level & local service coordinators
16. Data needs to be used in a way to identify problems proactively; there should be a neutral person who can hear consumer needs without bias or fear of reprisal
17. Develop a Consumer info line for advocacy
18. Information on what community services are available and are not available and length of waiting lists should be aggregated locally for planning
19. Share data and models of successful providers
20. Lists and ratings of providers of publicly funded programs & services, and make available to everyone

ISSUES THAT HAVE NOT BEEN PREVIOUSLY DISCUSSED

FRAUD AND ABUSE

1. Must set forth how to deal with Fraud and Abuse. Must answer questions:
   - What happens when abuse found?
   - What can and should be done about it
   - What is currently being done?
   - What are the criteria?
2. Must design an enhanced reporting system (whistle blowing) without retribution
3. Ombudsmen in institutions are working too close with the institutions
4. Establish where complaints about nursing homes can be directed.
5. There must be protection for patients and family members reporting problems, e.g., investigating complaints associated with negative clinical judgments
6. Must investigate why requests are made for transfer AFTER the transfer is made and the patient is safe – then follow up/ investigate

OTHER RECOMMENDATIONS

1. Improve and provide a broader range of services especially in rural counties.

2. Need more good nursing facilities –the good ones must be given recognition, excellence awards, and incentives
3. Provide incentives for providers
4. Give recognition to good providers
5. Award good processes, best practices

Olmstead Work Group Meeting
Sacramento, February 13, 2003

RESPONSE TO THE 2/10/03 DRAFT PLAN

GENERAL COMMENTS

ADD:

- Add COCO recommendations
- Update strategic plan as necessary
- Identify what depts. we are talking about
- Add Housing & Transp. re strategic plan
- Who will monitor strategic plans re/Olmstead
- Who reviews data needs & how community knows outcome
- Add grass roots coalition
- Need LT process of incorporating integration
- Need additional funding-using individuals who are recipients of services as part of process in overseeing olmstead plan-process
- Need sttement of commitment of state leaders
- Include specific dates for actions
- Add specific language on data
- Make stronger statement and classify needed info.
- Identify legislation needed to promote/assist goals/objectives of Olmstead Plan
- Identify W & I codes that impede the implementation of Olmstead and prohibit the potential of “money follows the person” and what actions need to be taken to support “money follows the person”
- Identify cost savings in budget cuts, i.e., costs for nursing vs. alternative care
- If the Long Term Care Council or other body is looking at the implementation of this plan, consumers of all the disability groups need to be members of the Council
- Review proposed budget cuts and analyze their impact in terms of compliance with Olmstead
- Review Plan in context of President’s Freedom Commission’s report
- Review current grants that are available to promote Olmstead goals
- Add TIMELINE for reporting back to stakeholders
- Review other St’s O’ Plan & glean good ideas/pitfalls
- Look into Rider 37 – money following the person consult Tx on this.
- Define process of “money following the person”

- Need system on analysis of data regarding assessment, svcs, unmet need, community capacity,-focus on diversion similar to DD system & community options. Laws in place to implement for diversion-just do not have resources larger array of options for DD pop vs. services for others
- Be committed to use of federal funding-use of matching state funds prior to seeking & being awarded funds.
- What does the plan mean in the big picture-funding & implementation issure & where do we go from here-what is commitment of state
- Put in beginning-include cultural competency all training
- Need steps that include revision of plan on ongoing basis.
- Create ma universal system for LTC – including standards for navigating system and integration of funding systems and services
- Use CMS language in overall document
- Planned activities: what are the actual proposed new actions vs. current activities
- Need to educate the public regarding the availability of & right to a broad array of community-based services
- Action step: produce media to support Olmstead activities
- Define "qualified & knowledgeable" thoughout the document.
- Include the family and authorized representatives when choices made
- Define who is responsible for assessment
- How will the state use MDS data?
- Training assessors to capture all information provided by the consumer whether it is available or not
- Eliminate any restrictions on who can provide svcs when consumer driven

CHANGE:

- How often will stakeholders have opportunity to review plan
- Annually – revise the plan
- Quarterly monitor implementation of the plan
- Define stakeholders
- Define who educates activists
- Specify who everyone is-everyone a disability *need to define everyone in general plan
- Change "should" to "must": Consumer ~~should~~ <u>will</u> be involved in the planning
- Policy on available an array of services: permit institutional care & choice for comm.; do not impose community placement if not desired

<u>ASSESSMENT</u>

ADD:

- Explain what is meant by each of the items, i.e., PASAR
- See COCO's response on this an all sections
- Add Ombudsman & HICAP

- Add who & how (stakeholder involve).
- What will be done with database (Add centralized)
- Add info on family dynamics re System of Care/Assessment
- Identify % of SNF beds that STATE will close & timeframe
- Guiding principles:
- -family, surrogate decision makers-include GP-promote consumer directed ass vs. involvement.
- "add family/conservator" to choice by consumer-authorized representatives, family by choice
- Policy goals: to determine supports & svcs needed to remain in community
- Add PASAR II information and use in all NF/IMD's.
- ADHC visits-person to leave nursing home may try ADHC services on trial basis-use this process
- Assessments should include information on available HCBS waivers
- Use IPP in this #for consistency-global process or use of IPP-look @ this.
- Be clear on indiv who R part of indiv. Dev. Team
- Convene focus workgroup of those on waivers, assessed, rejected, to determine what works, what does not work-indiv. on waivers incl.
- Train all Medi-Cal staff in Olmstead process
- Use plaintiff language to proposed closure of Agnews
- Include other living arrangements as a broad option-assess for svcs & supports to adequately serve them.
- Add resources-#6-identify, establish a state office to ensure that all individuals. w/disabilities are served in most integr. Setting 1st priority to those in nursing homes or at risk
- Use resources to look at diversion from nursing home to community placement.-goes back to training MC staff
- Proposal to develop design for new state office.
- Send RFP to a group to do cost assessment of community vs. institutional care
- Future expansion of Case Management Linkages.
- Take data on people in nursing home who only need custodial care and calculate how much cheaper it would be to serve/house in the community.
- Send letter to nursing home residents outlining their options for alternatives for living in the community.
- Find out barriers to assisted living for all ages. Guild in financial support. Incentivize housing and apartments.
- Ombudsman – grievance and appeal process by consumer family/partner
- Look at Texas and Oregon that made changes without additional dollars.

CHANGE:

- Advise all patients/reps in SNFs/Inst. (Educ. & outreach before ASSESSMENT
- Outreach plan – who does it?
- Change to all persons at risk of needing – intervention (See # 2 & 3 pg. 5)
- Who will do IDPs – person centered planning
- RFP would require stakeholders input in tool dev.
- Tie into oversight of SNFs – compliance with req.
- Add hospitals, physicians & CBOs
- Move #1 from Actions to a Planned Activity for purpose of informing people of plan, resources
- In RFP require tool be described w/stakeholders involvement
- Oversight tool to ensure nursing home cooperation
- Develop linkages protocols between nursing facilities hospitals/physicians office

DELETE:

- #7 In Gov. Budget – not nec.
- Assumes Conclusion

COMMUNITY/CAPACITY

ADD:

- 300 additional waiver slots not enough (COCO)
- Address hospice care in other populations
- Remove reg. Barriers for conditions not allowed
- Add “appropriately trained staff”
- Confront wait lists before they happen
- Develop, in conjunction with consumers and advocacy groups, a tree-tiered reimbursement package
- Codify difference between board and care and nursing regulations
- Keep same service coordinator throughout service changes
- Provide more consumer friendly long-term care
- Identify services waiting list and compare to capacity
- Remove marriage penalty, barriers to low-income couples not eligible for Medicaid,
- Put Best Practices from other states on web
- State examine contracted providers
- Develop housing action plan based on current housing stock
- Replicate LA County intensive MSSP & IHSS post-acute management team
- Increase transportation. State set paratransit standards for state regarding turnaround time and other issues

- Low-cost housing

CHANGE:

- #11.Who implements – opportunity for stakeholder impact
- Adjunct Explore 504 for home modif.
- Clarify #8 – bedridden
- #12. Clarify "model" to address ARONER bill – pull out critical elements city & county housing & release within 90 days to local planning Depts.
- #13. Explain PACE – what is it?

- Who, how, when & timeline (already in process) AB 925 – Aroner
- Include community integration & non-discrimination clause
- Assess overall ties between activities surrounding development of housing with issues of mobility.
- Add "private" funding sources
- Add "all ages" of disabilities
- Address hospice care for other populations
- Add who is implementing Prop 46?
- Explain 504 for home modification
- #13. Explanation needed
- #14. Add clarification – bldgs not svcs on equipment
- No # - explain start-up options for programs and equipment
- #15. Explain it
- #17. Who's partnering? Explain
- #18. Verify state authority, add, include community integrations, nondiscrimination clause
- Better explanation needed of AB 499 project
- No # - obstacles/barriers for receiving care by other populations – individuals w/MS,etc.
- #9. expand to other consumer groups
- #8. clarify bedridden
- #12. develop model language
- #12. release critical components to local co. planning w/in 90 days
- #13. expand to other than Elderly
- #2. eliminate institutional ? at state level
- #21. who is providing block grants how communicated to counties. Clarify
- #22. Who, timeline, what is outreach plan Olmstead connection expand to include RNs, CNAs, other programs
- Guiding Principles: fully funding services & supports – whatever team determines is appropriate for person
- Services should support individual, not0 take care of them
- Address the issue of a person who is employed & loses services/supports: evaluate level of support & impact on the individual. If they desire self employment : do not penalize people for trying to work.
- Stop cutting community svcs & lifeline supports like SSI

- Develop & implement full array of svcs
- Establishing 10 PACE sites in CA-rather than using MD's, nurses for house calls, use unlicensed indiv to do this
- Delete word long-term in est. 10 pace sites.
- #1 design models put into 2003
- #2CMS into put into 2003
- #26-State also supporting "federal permancy –add this- & utilization
- Support efforts to that allow non-govt entities to implement LTC integration pilot projects.
- Add wraparound svcs to allow transition to community
- Evaluate need vs wait list for NF waiver slots & barriers to this waiver based on past exp. F/u data on unmet need for NF waiver
- #2 apply & appropriate state funds for federal funding opportunities language to this
- add "incorporate ILS program with mandate to regularly assess move to less restrictive setting"
- specify funds to be assigned to Olmstead for home modification; don't require reversion to previous condition on sale, instead list on public, interactive data base that accessible units are available
- expand to aged and disabled; add community colleges and state colleges
- New # - to minimize institutionalization/reinstitutionalization add max hours awarded for first 90 days of transition
- 2. Who will do outreach. Who will provide training & created, what in 2003 timeline
- No #, identify what is happening regardless of funding, etc.
- No #, open the IHSS registry to the community. Add fee to fund registry
- #11. COCO – what does this have to do w/Olmstead? COCO – Add linkage
- #7. Recognize? Funds available for deflection purpose
- #11. What it is? Who is served?

DELETE:

- 7 & 8 – don't make board and care into a nursing home!

QUALITY ASSURANCE

ADD:

- #3. How (COCO)?
- #4. Address IHSS workers dollars to pay – should remain optional. (mandate check/client option)
- Duplicates #5, pg. 11
- How does it relate to Olmstead
- Who review strategies, plans for these depts?
- #2. Who will monitor/review strategic plans re Olmstead
- #3. Who reviews data needs, let public know of outcome

- #3. Add customer satisfaction complaint
- #4. Add more than just “assess.” “Provide training”
- #4. Need more “hands on training”
- No # - encourage all programs to expand language (-website-)
- #1.Public authority shd be monitored to ensure that training done
- #3. COCO comment how related to Olmstead
- #5. How it related to Olmstead & quality assurance &
- #5. Include elements of measuring deviations – where you are where you want to be
- No # - add assess overall ties between activities surrounding development. of housing, w/issues of mobility
- Advisory Panel including consumers with stipends to establish standards
- Not just for mental health but for all disabilities covered by the Olmstead Plan
- #4. Should be moved to 2003 for those programs such as Public Authorities that are already funded
- General recommendation: Encourage all programs to expand languages of websites

CHANGE:

- #1. Provide funding to Public Authorities in counties that have them in order to develop training as mandated.
- #5. How does it relate to Olmstead?
- Capture/measure deviation from where you are –want to be.
- Get Link to CMS website re Quality assurance)
- #10. What does this mean – clarify? (Age inclusive)
- #4. Explain funding options
- #4. Strengthen criminal record check – for own home care client/s option
- #5. Expand to other than other just DDS
- #6 What it means – how relates to Olmstead
- #8 move to # 5 on page 11
- #10 . Clarify 1 and A/R and CAIRS, distinguish between client groups being served
- #6 Add housing/transportation availability
- #11 Develop grievance procedures and appeals processes regarding level of care, that operate outside the purview of the provider and the ombudsman program, that include consumers and provide for legal adjudication, whether in the court or through arbitration
- #1 Specify what programs/which 3rd parties?
- #2 Clarify AB 1692 mandate re Public Authority/$ for registry (move up to 2003 – Activities)
- Add customer service satisfaction component
- Expand to include “hands on” training.

TRANSITION

ADD:

- Want to identify what is ongoing
- Add maximum hours awarded for 1st 90 days of transition (Reg Change) to deflect/minimize re-institutional.
- #2 Who will do outreach/training & timeline for 2003?
- #7 Add crisis funds (deflection)
- Open IHSS registry to community ; add a small fee to fund this

CHANGE:

- #8 change “persons with dev. disabilities”
- #11 How does it relate to Olmstead? (define more clearly)
- 211 coming
- Linkages

Olmstead Work Group Meeting
Sacramento, February 28, 2003

Response to the Draft Plan of February 24, 2003

GENERAL COMMENTS

General Comments:

- A framework is not a plan
- No timelines and no objectives
- What should the roles & responsibilities of consumers be? Include how it would be done. This is integral in plan – include as pare of LTC or subcommittee for oversight
- The DD Model works – why not build on this model?
- Good wisdom in putting in existing activities so legislature can see what is being done & what still needs go be done.
- Shift from facility based to community based services -- could do this on a percentage basis from current programs with long timeframes. D it without new monies or new programs
- Use planning to change people's minds & start new thought processes
- With services supports, make supportive for individual & not punitive so the person can be productive and live independently in community
- Put powers together to make the plan happen

DATA

- Letter (b) troubling – cannot readily determine
  - ✓ Expand to include those who later identify com. placement as their choice
- "Treating professional..." language not consistent with assessment language
  - ✓ New language "those whose assessments have rec. community living"
- Rick Specter suggested data be broken out by service sector (define)
- Incorporate data re why individuals leave Assist. Living. (Florida plan) – how many and why?
- Also, IHSS to SNFs
- Include info on #'s & reasons ind. not able to participate in Nursing Home waivers
- Analyze cost savings – look at aggregate of all funding
- Analyze statewide (elderly) costs for community care
  - ✓ Based on area
- What prevents Medi-CAL $ from use community care

- Additional element of data re costs versus savings, inst.
  - ➔ community
- Data on funding should reflect continuum of care
- Need funding mechanisms that follow system of care
- have to be interactive
- concomitant
- Rather than just saying State will convene a meeting – should say "& we will continue O Planning based on data" (not just l mtg j)
- Revise Plan, etc. – continue in public venue
- identify specific date for individuals living in publicly (this has not been defined) funded institutions or when plan completed, add timeline for determining this.
- people at risk who are 0 currently eligible for svcs due to finances.
- timelines; relationship to LTC-C data group commitment to use data, not conditional; nail the consultant; key to success

COMPREHENSIVE CARE COORDINATION

- Avoid wait lists (not waiver dependent)
- Review statutes which may be barriers to nursing home trans. Implementation
- Implications of realignment?
- Item "m," pg. 5, annual updates (Rick – pick up Fed. req.)
- "...or more freq. if indicated by sig. change in participant or needs."
- Emphasize that parts of plan can be implemented without add. $ (look at Texas)
- Utilize existing statewide data to start transition in timely fashion (DATA ANALYSIS – costs $)
- Do we need additional resources when we are saving $ by moving people out of nurs. homes -> Commun
- IHHS Authorities have data
  - ✓ All counties may have data avail.

- Policy goal: include comprehensive strategic plan – include thru plan to appropriate areas – this will lead to development of goals & objectives
- Overall – develop and/or utilize "regionalization" for plan development & implementation – this way we cover entire State
- 2 goals-planning & implementation – separate out w/ timeline for each goal-by April 1, 2004
- NF listed as the institution being addressed, but what about other institutional settings?
- Revise goal to relate to coordination of services &CA to have a comprehensive care system w/an array of community based services.
- -pg6 next to last bullet-does this defeat or plaintiff LTCI pilot goals – evolving process

- Enact legislation for PACE-like projects for everyone & not just elderly.

ASSESSMENT

- Last bullet – DHS will partner with advocates/to ensure residents in inst. Will both receive & be able to understand options.
- Conversely, inst. option needs to be included in provision of information.
- And rehab fac. & discharge planners
- Refer to COCO's written comments & reflect
  - ✓ "people should not be req. to make decisions without sufficient info."
  - ✓ "Planning parameters"
  - ✓ COCO
- In the event, if Agnews closes DDS will assess…
- COCO Commun. should not be required to move/make a decision prior to participating in an assessment
- Assessment should be done annually – (also see language introduced by CMS re: Fed guidelines)
- Indicate specifically a tool will be developed for the comprehensive assessment-tools/processes must be comprehensive & be inclusive of elements a-p
- Policy goal-plaintiff language to include indiv being assessed to make informed choice regarding community placement always include wk toward universal assessment tool & presumed elig for svcs-could be determined thru assessment as though "they are entitled to svcs."
- Pg 9-apply for independence plus waiver for everyone-not just DD pop:-also looking @ IHSS advance pay for an indep plus waiver
- Involve consumers when looking at reviewing existing assess. procedures.
- Pg9 I-develop a program of peer support

DIVERSION

- Expand last bullet – pg. 11 to include "any institution" not just Dev. Centers
- Apply to CMS for HCBS waiver & other grants re Medi-CAL funding for Assisted Living
- Replace "should" with "shall"
- LTC council to review current procedures for effectiveness (1st bullet language plaintif to this language) of diversion if care planning procedures are in place, why do we need to review & why have pilot projects if u are doing this – just a comment
- What about at risk individuals, assessments & timeliness in being placed on waiting lists-needs to be added
- For diversion, need hotline or resources to access immediately for individuals as risk-get put on a "list" early to help divert them-cm&dc planners should have access to this resource

TRANSITION

- Add "choice"
  - ✓ If they do not object 'is Olmstead language **????**
- "F" – add: and furnished with a list of contracted community care providers
- Downsizing facilities
  - ✓ DDS to identify large facilities
  - ✓ Assess individuals for transitioning to smaller living arrangements at their choice unless there is an objection
- Educate planning team training re: community options/resources
- Whose discharge planning procedures will be reviewed? --Those that the state is responsible for? If so, who are they? Will state review internal vs. Community providers-not clear on goal-need to revise.
- New goal: Have LTC council develop a DC planning model & provide to individuals consistent w/Olmstead principles, monitor implementation (make a condition of MC participation)-include time line-require this of all who receive MC monies-minimal standards to be met
- Need policy for actually transitioning people out of inst.
- Need LT goal for downsizing large residential care facilities in general
- Last bullet pg13-allow other areas for people to test for successful transition such as trying transportation, other svc areas

COMMUNITY SERVICE PROVIDERS

- Last 3 bullets should be linked to data - Resource exp. should be based on data re unmet needs
- Re-write waivers (in conjunction with stakeholders) when they expire
- Waitlist analyses should include whether or not programs are fully understood as options & waitlist reflects need
- Clarify to include "option" (#7)
- Expand Supported Living Options for persons with Development Disabilities
- #300 needs to be higher to expand to immediate needs
- Identify local federal actions in addition to State
- Develop programs to develop nurses forgive student loans based on # of years of service

Add "restore" in addition to expand related to nutrition

HOUSING

- Add universal design HCD – create model
- In Appendix/SB 1687 (1996-Marks)
- Re access req.
- Enforcement of existing laws for home modif. access
- Educate HUD authorities on access requirements.

- Monitor compliance/performance
- Enforcement of Fair Housing laws

MONEY FOLLOWS IND.

Add new #2

- Implement Money follows Person as quickly as feasibly possible
- Utilize free expertise (Geraldo Cantu – Tex. Dept. Health; Mary Jean Duckett, DMS – (410) 786-3294
- Intro. Budget Trailer Bill to allocate MFP funding for x number particip.
- Generate a letter to all SNF res. interested in re transition services
- States do not use pilot programs to imp. (Budgetary Transfer for DHS)
- Money saved should stay in fund for this purpose not revert to general fund
- Identify low cost methods to implement MFP, like other states
  - ✓ Convene a group of stakeholders to dev. a tiered reimbursement rate to RCFE interested in becoming
  - ✓ providers
  - ✓ Train IHSS workers & Medi-CAL eligibility specialists to determine eligibility of MFP who want to apply for nursing home transition funding
  - ✓ Provide a list of SNF residents of community options
- More to diversion section
  - ✓ DHS will propose to CMS to reverse the institutional bias. Will explore the details to put in the letter.
  - ✓ Identify the elements of institutional bias

CONSUMER INFO

- Graduate workers wages based on service
  - ✓ Buy-in rates should not be criteria
  - ✓ Share of cost ratio & rates
- Report cards on provider quality should be available to consumers
- Expand last bullet to be comprehensive for broader Olmstead Planning
  - ✓ Appoint Olmstead Planning body (part of LTC)
- Revisit share-of-cost ratio & rates
- DD System & inclusive of other populations lists of possible service providers. (all vendors) now.
- Report cards on quality of services & providers
- Dedicated ‘Olmstead’ professional

QUALITY ASSURANCE

- Suggested change of name to “quality of life”
- Bullet 1, needs consumer input on what is missing
- Curricula in state funded inst. of higher learning include 2 sem. of Olmstead. (CEUs for Admin.)

- LTC should have annual reports available to the public & providers of service – including a section written by consumers legislature
- Health prof etc & etc – Advocacy Groups Educators
- Public distribution of results
- Include consumer & stakeholder input